Latinas and Breast Cancer Outcomes: Population-based sampling, Ethnic Identity and Acculturation Assessment

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Abstract

Purpose—Latinas and African-Americans with breast cancer, especially those of lower socioeconomic status and acculturation, have been underrepresented in studies assessing treatment satisfaction, decision making and quality of life. A study was designed to recruit a large and representative sample of these subgroups.

Methods and Materials—Incident cases were selected by Rapid Case Ascertainment (RCA) by the Los Angeles SEER Registry in 2005-2006, with oversampling of Latinas and African-Americans. Patients were mailed a questionnaire and $10 incentive 5-6 months after diagnosis; non-respondents were contacted by telephone. Multivariate analysis was used to assess possible response bias. The RCA definition of Hispanic origin was validated by self reports. The SASH acculturation index for Latina respondents was used.

Results—1,698 eligible breast cancer cases were selected and 1,223 participated for a response rate of 72.0%, which varied little by race/ethnicity. Age, race/ethnicity, and clinical factors were not associated with response; however respondents were slightly more likely to be married and from higher socioeconomic status census tracts than non-respondents. The RCA definition of Hispanic identity was highly sensitive (94.6%) and specific (90.0%). Lower acculturation was associated with lower education and literacy among Latinas.

Discussion—High response rates among all subgroups were achieved due to use of RCA, an incentive, extensive telephone follow-up, a native Spanish speaking interviewer, and a focused questionnaire. The low acculturation index category identified a highly vulnerable subgroup. This large sample representing subgroups with greater problems will provide a basis for developing better interventions to assist these women.

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Keywords

Breast Cancer; Treatment Decision; Latinas; Acculturation; Survey Research; Cancer Registry; Population-Based

Introduction

The use of regional cancer registries for oncology quality of care and outcomes research is growing because they can draw on large population-based samples with sufficient power and representation to evaluate important issues in vulnerable populations. Additionally, regional registries have experience in identifying and enrolling patients into studies shortly after diagnosis. (1, 2) These advantages have fueled a research agenda that addresses important clinical and health policy issues including quality of treatments, patient perspectives about care, transitions to survivorship, outcomes such as quality of life and survival, and racial/ethnic disparities in all of these issues (3-8). As the demand for more research in this area increases, methods to improve the representativeness of results are especially important. Key methodological challenges using cancer registries include sampling and identifying appropriate patients shortly after diagnosis, achieving high response rates particularly for minority patients, and deploying valid measures of ethnicity.

Latinos have been a particularly under-represented group in oncology quality of care and outcomes studies (9-15). Few studies have included sufficient numbers of Latinos to evaluate care experiences despite their increasing proportion among cancer survivors in the United States(10, 13, 16, 17) For example, there are virtually no studies with sufficient representation of Latinas in the large literature of quality of care and survivorship in breast cancer. This largely reflects the particular challenges of identifying and engaging this patient population in research. Sampling Latinos is challenging because ethnic identity (vs race) is not reliably available through information such as hospital and medical records. A second challenge is enrolling and engaging sufficient numbers of Latino patients in studies, especially patients with low acculturation who often have lower socio-economic status, a group as a whole which is less likely to participate in studies. A third challenge is developing valid measures of acculturation that capture the rich diversity of this population.

In this article we describe how we addressed these challenges in a large population-based study of quality of care and outcomes for patients with breast cancer diagnosed in Los Angeles County from June 2005 through May 2006. The aims of the overall study were to evaluate race/ethnic differences in patterns of treatment, patients' perspectives about decision-making and care support, and quality of life outcomes for women with breast cancer. We present results that inform methodologies for successful population-based registry research including how we: 1) selected a representative stratified sample of patients as they were being diagnosed, 2) achieved a high response rate among all racial ethnic subgroups, 3) assessed possible bias in survey response, and 4) assessed the validity of registry based ethnic identification and defined levels of acculturation among Latinas. Our methods and results will be useful to other researchers developing studies to evaluate cancer-related outcomes in diverse populations.

Methods

Study Population

Los Angeles County resident women aged 20-79 years diagnosed with primary ductal carcinoma in-situ (DCIS) or invasive breast cancer (Stage 1-3) between 6/1/2005-5/31/2006 were eligible for sample selection. Spanish-surnamed white, African-American, and Non-Spanish surnamed white women were included, while Asian and other racial ethnic groups were excluded due to their participation in other studies.

Sample Selection

The cases were selected by rapid case ascertainment (RCA) by the Los Angeles Cancer Surveillance Program (LA-CSP), the Surveillance, Epidemiology, and End Results (SEER) Cancer Registry for Los Angeles County. RCA is a method whereby cases are sampled, usually within a month of diagnosis, by registry field staff who manually review pathology reports at hospitals prior to their submission to the cancer registry. During the period August 1, 2005-May 31, 2006 all pathology reports at Los Angeles County hospitals were reviewed monthly for breast cancer cases meeting the eligibility criteria. Since the pathology reports could include diagnostic biopsies as well as surgical pathology reports, multiple pathology reports per case could be obtained. Using historical incidence counts to estimate the number of cases that would be diagnosed during the ascertainment time period, we determined that all Latina and African-American cases should be selected as well as an 11% random sample of Non-Spanish Surnamed Whites (NSSW) to obtain the desired sample size.

Different RCA strategies were employed for each racial/ethnic group. Because Latina (or Hispanic) status is not uniformly collected by the hospital at the time of diagnosis, we selected all pathology reports from women who were designated as Hispanic or Latina by the hospital as well as selecting pathology reports from women whose surname indicated a high probability of being Latina based on a list generated from the 1980 U.S. Census. To select African-Americans, we checked demographic information from the hospital database on all non-Latina or non-Asian surnamed women and selected all pathology reports from women designated as Black or African American. To select the random sample of NSSW from all of the remaining pathology reports, we provided all field technicians with lists of random numbers (generated using SAS RANUNI) that were programmed to accept 11% of all NSSW pathology reports consecutively screened. In total, 2,024 unique cases were sampled from the three racial/ethnic groups (Figure 1).

Determination of eligibility of sampled patients

Since cases selected at the time of RCA are not quality controlled to eliminate ineligible patients (i.e. those that are not primary breast cancer diagnoses, out of county residents, first diagnosed prior to the recruitment period, or with an ineligible histology or stage of disease), the sampled cases were linked about 6-8 months later to the quality controlled registry file to eliminate the ineligible cases (Figure 1). This was done after the survey had been sent and thus resulted in the disqualification of some survey responses. In addition, we excluded cases who died within 8 months after diagnosis, since this was the average time between diagnosis and patient contact. The earliest eligible diagnosis date was extended back to June

1, 2005, since many of the selected cases from when ascertainment began on August 1, 2005 had been diagnosed in the two months beforehand. As a result of the linkage, 258 (12.8%) of the 2,024 initially sampled patients were determined to be ineligible. The reasons included out of county residence (n=55), stage 4 disease (n=67), ineligible histology code (e.g. lymphoma)(n=17), diagnosis prior to 6/1/2005 (n=87), or deceased within 8 months of diagnosis (n=32).

The remaining registry-eligible sample of 1,766 cases included 796 Latina cases (based on the registry's definition), 459 African-American cases, 478 non-Spanish surnamed white cases, and 33 cases listed by the registry under other racial categories. Based on the registry's quality controlled database, the total number of incident cases who would have been eligible for the study during the period from 6/1/2005-5/31/2006, included 1,093 Latinas, 615 African-Americans, and 3,012 NSSWs. Thus, the final sample included 69.3% of Latina, 69.8% of African-American, and 14.2% of NSSW cases who would have been eligible for our study.

After initial contact efforts, another 74 patients were found to be ineligible for participation due to 1) physician refusal to contact (n=7); 2) patient did not speak English or Spanish (n=8), 3) patient was too ill or incompetent to participate (n=30), and 4) patient denied having cancer (n=23) (Figure 1). Thus, using these criteria, we defined 1,698 patients from the sample as eligible for analysis.

Assessment of representativeness of sample selection

Bias in sample selection may occur due to 1) cases reported from doctor offices and free-standing pathology laboratories which are not surveyed during RCA, which only obtains cases reported in hospitals, 2) possible delays in the availability of path reports at the time of RCA, and 3) if the randomized selection of NSSW was somehow biased. The representativeness of the sampled cases compared to all eligible cases diagnosed during the ascertainment period was assessed about 7-8 months after the sample was selected using registry variables (age, stage, vital status, date of diagnosis, race/ethnicity). Multivariate logistic regression was used to determine if any variables not linked to the sampling design independently predicted sample selection.

Patient contact methods

Physicians were notified of our intent to contact patients by a courtesy letter. If no objection was received, the selected patients were sent an introductory letter, survey materials, and $10 cash as compensation for the time and effort to complete the questionnaire. The patient survey instrument and introductory letter were translated into Spanish using previous translated versions of the validated questions included (e.g. the FACT-B). All patients who had a Spanish surname based on the U.S. census list were sent materials in both English and Spanish. The Dillman survey method was employed to encourage response (18). Specifically, the subjects were called a minimum of 5 times within 2-3 weeks of the mailing if no response was received, sent second copies of materials, and eventually offered a phone interview. Spanish speaking interviewers were used. Extensive tracing methods were employed to locate cases with incorrect addresses, nonworking phone numbers, or those

from whom no response was received and no contact was able to be established. The study protocol was approved by the Institutional Review Boards of the University of Michigan and the University of Southern California.

Acculturation Measure

In addition to race/ethnicity we also assessed acculturation among Latinas in the survey using the Short Acculturation Scale for Hispanics (SASH) (19) which consisted of 4 items that asked respondents (who indicated that they could speak any Spanish) to indicate their language preference on a 5 point scale that included the categories 'Only English', 'English better than Spanish', 'Both equally', 'Spanish better than English', and 'Only Spanish'. The four questions were: 1) What language(s) do you read and speak?, 2) What language do you usually speak at home?; 3) In what language do you usually think?; 4) What language do you usually speak with your friends? Using the results from the individual items, a polychoric correlation matrix was constructed to examine inter-item correlations. A summary score was calculated for each respondent that was based on the mean of their responses to all 4 of the items. Confirmatory factor analysis and validity studies, including bivariate distributions of categories for education attainment, country of origin, and parents' origin by categories of the SASH summary score, were used to characterize the acculturation-related differences identified by this scale for the Latina respondents in our population.

Calculation of response rate to survey and representativeness of respondents

The response rate was based on the number of respondents from among the 1,698 patients determined to be eligible. Subjects who refused to participate or who were unable to be located or contacted (after extensive tracing and multiple mailings of the questionnaire and follow-up phone calls) were considered non-respondents. Using available registry variables the chi square statistic was used to identify univariate differences in characteristics between the respondents and non-respondents and multivariable logistic regression was used to determine independent variables that predicted response.

Results

Representativeness of RCA Sample Selection

Using a multivariable logistic regression model (Table 1) we found that the only non-design factors associated with RCA sample selection were related to treatment received, age, and tumor differentiation. Those with no surgery, older age, and unknown differentiation were less likely than their counterparts to be selected while those receiving radiation or hormone therapy were more likely than those not receiving these treatments.

Response Rates

The survey was completed by 1,223 or 72.0% of the 1698 eligible patients (97.8% of whom completed a written survey and 2.2% of whom completed a telephone survey). A total of 296 or 17.5% of the patients refused participation and 179 (10.5%) were lost to follow-up after extensive tracing efforts. Based on the race/ethnicity definition at the time of sample selection, the response rate for Latina women was similar to all non-Latina women (i.e. AA

and NSSW combined) (71.4% vs. 72.7%, p=0.56). However, within the non-Latina group, the response rate was significantly higher among NSSW than among AA (77.6% vs. 68.2%, p=.002) (Table 2). Among the 601 Hispanic women completing the questionnaire, 300 completed the English version and 301 completed the Spanish version. Although use of the telephone was relatively low (3% were completed by phone overall), it was an option used more often for those responding in Spanish than in English (6% vs. 2%). Extensive recontact of all respondents who returned an incomplete questionnaire was also conducted by telephone in order to complete critical missing questionnaire items. In total, 24.1% of respondents sent back incomplete questionnaires and missing data were obtained for 262 or 88.8% of this group.

Respondents vs. Non-respondents

Registry information on all eligible selected patients was used to compare differences between respondents and nonrespondents. There were differences based on age at diagnosis, race/ethnicity, and Spanish surname (Table 3). However non-respondents were more likely to be never married than respondents, and patients from lower SES census tracts were slightly less likely to complete the survey than those from higher SES tracts. There were no differences in response based on receipt of chemotherapy or hormone therapy or tumor grade; however non-respondents were more likely to have stage 2 or 3 disease compared to respondents, were slightly more likely to have had a mastectomy or no surgery, and were less likely to have received radiation therapy. When these variables were included in a multivariate logistic regression model to determine independent predictors of response, we found that response was higher among older patients (p for trend=0.02), those with lower stage disease (p for trend=0.003), and among currently married women (p=0.03). Socioeconomic status of census tract, type of surgery, and radiation therapy were unrelated to response in the multivariate model.

Hispanic Identification Among Respondents

Using the self-reported identification of Hispanic ethnicity from the survey as the gold standard, the sensitivity and specificity of RCA sample definition and three registry-based definitions were assessed (Table 4). The first comparison was made with the initial determination of Hispanic identity at the time of RCA sample selection based on a combination of Spanish surname and hospital defined Hispanic ethnicity. The sensitivity of the approach was 94.6% compared to a specificity of 90.0%. The predictive value positive was 89.2% and the predictive value negative was 95.0%. Sensitivity was slightly lower (89.5%) and specificity a bit higher (92.3%) when we based the definition solely on the RCA determination of Spanish surname. Similar results were found when just using the SEER Spanish surname definition. However, when the SEER NHIA (NAACCR Hispanic Identification Algorithm) variable was used, the sensitivity was 97.7%, and specificity was 90.7%. The NHIA variable (NAACCR Hispanic Identification Algorithm) was developed by NAACCR (North American Association of Central Cancer Registries) and utilizes both direct and indirect methods of determining Hispanic origin(20). The algorithm is based on the NAACCR variables for Spanish/Hispanic Origin, Last Name, Maiden Name, Birthplace, Race, and Sex.

Latina Acculturation Measure

Among the 601 respondents who were initially identified as Hispanic at the time of sample selection 565 of them self-identified as Latina based on their survey responses. Forty five of them did not answer the 4 items of the SASH because they indicated that they spoke only English on a screening question (and were given the code of 1= 'Only English'); only 4 of the remaining 520 failed to complete all 4 items. Responses to each of the 4 items in the SASH were based on a 5 item Likert scale (ranging from 1='Only English' to 5='Only Spanish'). Given the ordinal nature of this scale, a polychoric correlation matrix was constructed which showed very high interitem correlations (all >.94). The factor analysis of the polychoric correlation matrix showed one dominant factor with very high loadings and uniqueness components of less than .07 for all items.

A SASH summary score was calculated by averaging responses from the individual items. Analysis using a non-parametric multilevel ordinal factor model showed that the summary scale values fell into a bimodal pattern separating the population into two groups that spoke predominantly English or Spanish. The bimodal distribution is evident in Figure 2 which shows the distribution of mean SASH summary scores (overall mean was 3.4, sd 1.5). The red line indicates the recommended cutoff (2.99) by Marin (19) to discriminate less acculturated from more acculturated Latinos, however about half of the respondents in our sample (53.8%) had average scores of 4 or higher on the five point scale and therefore we used 4.0 as the cut-off for our subsequent analyses. About one quarter of the Latina sample (27.9%) had scores less than 2 indicating that they spoke English more than Spanish; while only about one fifth (18.3%) had intermediate values between 2 and 4.

We validated the SASH score categories by examining the distribution of other variables that may be likely to be related to acculturation (Table 5). The table also suggests that there are two distinct groups identified according to our cutpoint of 4.0. Respondents in score ranges of 4 or more (strongly preferring Spanish) reported the lowest levels of education, being US born, and having either parent born in the USA. By contrast, respondents with scores below 3 (strongly preferring English) reported much higher levels of education, being US born, and having one or more parents born in the USA. The group with scores between 3.0-3.9 appear to be a group, largely foreign born (similar to those with scores of 4.0 or greater), but with education and literacy levels similar to the English preferring group with scores under 3.0. Approximately 20% of these women said they needed help with written information (similar to those with scores <3.0), whereas 44% or more of the respondents with scores of 4.0 or greater needed such help.

Discussion

We have demonstrated that a highly representative sample of cancer patients can be selected as they are being diagnosed using RCA; a high response rate can be achieved among all racial/ethnic groups; and that Latina ethnicity is a valid variable in registry databases. Furthermore, we found a bimodal distribution of Latinas in Los Angeles County with regard to level of acculturation which was highly related to educational level and health literacy. Over half of the self-identified Latinas indicated that they preferred to speak Spanish over English. The representative nature of these respondents is supported by data from the

California Health Interview Survey (CHIS) which found that 50% of Latina women in Los Angeles County in 2003 spoke English not well or not at all(21). The study of this vulnerable group will be especially important since previous research has indicated that low acculturation is related to reduced cancer screening and poorer quality of life among Latinas(8, 22-26).

The results of this study have already found large differentials in decision making and perceptions of information and care support between the low and high acculturated Latina women (27) (28). This highlights the importance of achieving a representative sample of minority patients.

Studying cancer survivors can be difficult due to illness, loss to follow-up, and unwillingness to participate when confronted with the all of the stresses of cancer survivorship. Minorities and those with lower income and education tend to be less likely to participate in research studies and clinical trials(9) (29) (30), and there may be factors associated with a greater lack of trust in research studies among African-Americans and Hispanics (31). Our study demonstrates that, despite these obstacles, a representative sample can be achieved. Aspects of this study that insured its success included ascertainment of cases by RCA which allowed contact relatively soon after diagnosis (thus minimizing loss to follow-up); a professionally formatted and translated survey instrument with content that was engaging to recipients; a rigorous data collection method based on the Dillman method including follow-up mailings of surveys and calls to non-respondents, call backs for missing data; and the dedicated commitment of staff including a native Spanish speaking study coordinator. Of note, despite the availability of a full telephone interview, nearly all respondents preferred to complete a mailed version of the survey. Despite this preference, having the telephone available as an option was important to achieving the high response rate that we did, especially for the Spanish speakers. Studies that rely on a single option for response, or a more lengthy survey, may achieve a lower response rate. For example, another study based on an RCA sample of Los Angeles patients that involved a 90 minute telephone interview achieved a 64% response rate.(3).

The validation of the registry Spanish ethnicity variable in Los Angeles is also an important finding from this study since sample selection was based on this information. Our PPV of 89.2% when using both Spanish-surname and hospital ethnicity or 91.3% based on Spanish surname alone were higher than found in a previous registry based breast cancer study in Utah and New Mexico where a PPV of 82.3% was found for Spanish surname (32).

Our study also is the first to evaluate the reliability and validity of the SASH in a large population-based sample of Latinas with breast cancer in Los Angeles County. The reliability of the 4 item scale was very high and confirmatory factor analysis indicated one principle component. Indeed, the between-item correlation was so high that one or two questions (perhaps those related to general language use) could be used in place of the item scale. However, it is important to note that the short scale was very easy to complete as we had incomplete data for only 4 of 565 respondents (less than 1%). There was a broad distribution of scores across the 5 point score range with obvious clustering of respondents around predominantly Spanish speaking and predominantly English speaking with about a

quarter of patients with intermediate scores. Higher scale scores were associated with lower education attainment, being Mexican or Central American born, living in the US for fewer years, and having parents born outside the US, and lower health literacy. One key issue raised by our study is the choice of cutoffs for the 5 point scale. The developers of the SASH have recommended a cutoff of 2.99 with no midpoint representing biculturalism(19). However, our results suggest caution in the selecting the cutoff point for different Latino populations in different studies. In our study we drew the cutoff point at 4 or more because this identified a large group (half the Latina study population) who had particularly low education and health literacy. In some studies this group may be particularly important to identify (27) (28). Investigators may need to establish other cutoff points on the SASH scale that optimize its use with regard to the research questions and target population.

An important limitation of our study related to the acculturation measure is that the target population was restricted to Latinas with breast cancer in LA County. Obviously, men were excluded from the sample. Furthermore, the immigrant experience of LA County (predominantly Mexican and Central American) may be different than other Latino communities where they may be more representation from other countries from the Caribbean or South America. We expect that the SASH would perform well in these populations but that question cannot be addressed in our study.

Limitations of the RCA method should be noted. This method may not be available in all settings due to different capabilities of cancer registries. When it is able to be implemented there are some methodological limitations. Since cases are selected prior to registry based quality control measures, patients are initially included (and resources spent contacting and interviewing them) that are later found to be ineligible. However, in our study, this proportion was less than 13%. Furthermore, all potentially eligible patients are not able to be selected by the RCA process. Nevertheless, we have demonstrated that the sample obtained in Los Angeles was highly representative of the total incident cases.

Finally, despite our high response rate, we did find that some differences in response according to age, marital status, and stage of disease with older, married, and lower stage patients more likely to participate. Since these women may be expected to have more social support and less disease burden than nonrespondents, the findings from the study may conservatively state the extent problems facing breast cancer patients.

The study methods are applicable to other studies of cancer survivors with a goal of oversampling minority patients and indicates the need to assess acculturation in Latinas. Long term follow-up of our cohort will prove to be especially valuable, given other research indicating continuing racial/ethnic disparities in breast cancer survival over time (4) (7) (33).

Acknowledgments

References

1. Lipscomb J, Donaldson MS, Arora NK, et al. Cancer outcomes research. Journal of the National Cancer Institute. 2004; (33):178–97. Monographs. [PubMed: 15504928]

2. Wingo PA, Howe HL, Thun MJ, et al. A national framework for cancer surveillance in the United States. Cancer Causes & Control. 2005; 16:151–70. [PubMed: 15868456]

3. Yoon J, Malin JL, Tao ML, et al. Symptoms after breast cancer treatment: are they influenced by patient characteristics? Breast Cancer Research & Treatment. 2008; 108:153–65. [PubMed: 17492377]

4. Ell K, Xie B, Wells A, Nedjat-Haiem F, Lee P-J, Vourlekis B. Economic stress among low-income women with cancer: effects on quality of life. Cancer. 2008; 112:616–25. [PubMed: 18085642]

5. Fatone AM, Moadel AB, Foley FW, Fleming M, Jandorf L. Urban voices: the quality-of-life experience among women of color with breast cancer. Palliative & Supportive Care. 2007; 5:115–25. [PubMed: 17578062]

6. Ashing-Giwa KT, Tejero JS, Kim J, Padilla GV, Hellemann G. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. Quality of Life Research. 2007; 16:413–28. [PubMed: 17279444]

7. Bowen DJ, Alfano CM, McGregor BA, et al. Possible socioeconomic and ethnic disparities in quality of life in a cohort of breast cancer survivors. Breast Cancer Research & Treatment. 2007; 106:85–95. [PubMed: 17260096]

8. Katz SJ, Lantz PM, Paredes Y, et al. Breast cancer treatment experiences of Latinas in Los Angeles County. American Journal of Public Health. 2005; 95:2225–30. [PubMed: 16257945]

9. Ashing-Giwa KT, Padilla GV, Tejero JS, Kim J. Breast cancer survivorship in a multiethnic sample: challenges in recruitment and measurement. Cancer. 2004; 101:450–65. [PubMed: 15274058]

10. Ashing-Giwa K. Can a culturally responsive model for research design bring us closer to addressing participation disparities? Lessons learned from cancer survivorship studies. Ethnicity & Disease. 2005; 15:130–137. [PubMed: 15720060]

11. Brown D, Fouad M, Basen-Engquist K, Tortolero-Luna G. Recruitment and Retention of Minority Women in Cancer Screening, Prevention, and Treatment Trials. Annals of Epidemiology. 2000; 10(supplement 1):S13–S21. [PubMed: 11189088]

12. Steiner J, Cavender T, Main D, Bradley C. Assessing the impact of cancer on work outcomes. What are the research needs? Cancer. 2004; 101:1703–1711. [PubMed: 15386303]

13. Aziz NM, Rowland JH. Cancer survivorship research among ethnic minority and medically underserved groups. Oncology Nursing Forum Online. 2002; 29:789–801.

14. Schultz P, Stava C, Beck M, Vassilopoulou-Sellin R. Ethnic/racial influences on the physiologic health of cancer survivors. Focus on long-term survivors of cervical carcinoma. Cancer. 2003; 100:156–164. [PubMed: 14692036]

15. Klausner R. Cancer, minorities and the medically underserved. The role of the National Cancer Institute. Cancer supplement. 1998; 83:1703–1706.

16. Shavers V, Brown M. Racial and ethnic disparities in the receipt of cancer treatment. J Natl Cancer Inst. 2002; 94:334–357. [PubMed: 11880473]

17. Ramirez A, Villarreal R, Suarez L, Flores E. The emerging Hispanic population: a foundation for cancer prevention and control. J Natl Cancer Inst Monographs. 1995; 18:1–9. [PubMed: 8562207]

18. Anema MG, Brown BE. Increasing survey responses using the total design method. Journal of Continuing Education in Nursing. 1995; 26:109–114. [PubMed: 7759621]

19. Marín G, Sabogal F, VanOss Marín B, Otero-Sabogal F, Pérez-Stable EJ. Development of a short acculturation scale for Hispanics. Hispanic Journal of Behavioral Sciences. 1987; 9:183–205.

20. NAACCR Latino Research Work Group. NAACCR Guideline for Enhancing Hispanic/Latino Identification: Revised NAACCR Hispanic/Latino Identification Algorithm [NHIA v2]. North American Association of Central Cancer Registries; Springfield (IL): 2005.

21. California Health Interview Survey. CHIS 2003 Adult Public Use File [computer file]. UCLA Center for Health Policy Research; Los Angeles, CA: 2005.

22. Ashing-Giwa KT, Padilla GV, Bohorquez DE, Tejero JS, Garcia M. Understanding the breast cancer experience of Latina women. Journal of Psychosocial Oncology. 2006; 24:19–52. [PubMed: 17088240]

23. Borrayo EA, Guarnaccia CA. Differences in Mexican-born and U.S.-born women of Mexican descent regarding factors related to breast cancer screening behaviors. Health Care for Women International. 2000; 21:599–613. [PubMed: 11813768]

24. Brown WM, Consedine NS, Magai C. Time spent in the United States and breast cancer screening behaviors among ethnically diverse immigrant women: evidence for acculturation? Journal of Immigrant & Minority Health. 2006; 8:347–58. [PubMed: 16645898]

25. Gorin SS, Heck JE. Cancer screening among Latino subgroups in the United States. Preventive Medicine. 2005; 40:515–26. [PubMed: 15749133]

26. Jacobs EA, Karavolos K, Rathouz PJ, Ferris TG, Powell LH. Limited English proficiency and breast and cervical cancer screening in a multiethnic population. American Journal of Public Health. 2005; 95:1410–6. [PubMed: 16043670]

27. Janz NK, Mujahid MS, Hawley ST, Griggs JJ, Hamilton AS, Katz SJ. Racial/ethnic differences in adequacy of information and support for women with breast cancer. Cancer. 2008; 113:1058–67. [PubMed: 18618494]

28. Hawley S, Hamilton A, Janz N, et al. Latina perspectives about informed treatment decision making fo breast cancer. Patient Education & Counseling. 2008; 73:363–370. [PubMed: 18786799]

29. Fair AM, Wujcik D, Lin J-MS, Egan KM, Grau AM, Zheng W. Timing is everything: methodologic issues locating and recruiting medically underserved women for abnormal mammography follow-up research. Contemporary Clinical Trials. 2008; 29:537–46. [PubMed: 18289943]

30. Pinsky PF, Ford M, Gamito E, et al. Enrollment of racial and ethnic minorities in the Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial. Journal of the National Medical Association. 2008; 100:291–8. [PubMed: 18390022]

31. Katz RV, Wang MQ, Green BL, et al. Participation in biomedical research studies and cancer screenings: perceptions of risks to minorities compared with whites. Cancer Control. 2008; 15:344–51. [PubMed: 18813202]

32. Sweeney C, Edwards SL, Baumgartner KB. Recruiting Hispanic women for a population-based study: validity of surname search and characteristics of nonparticipants. American Journal of Epidemiology. 2007; 166:1210–9. [PubMed: 17827445]

33. Janz NK, Mujahid M, Chung LK, et al. Symptom experience and quality of life of women following breast cancer treatment. Journal of Women's Health. 2007; 16:1348–61.
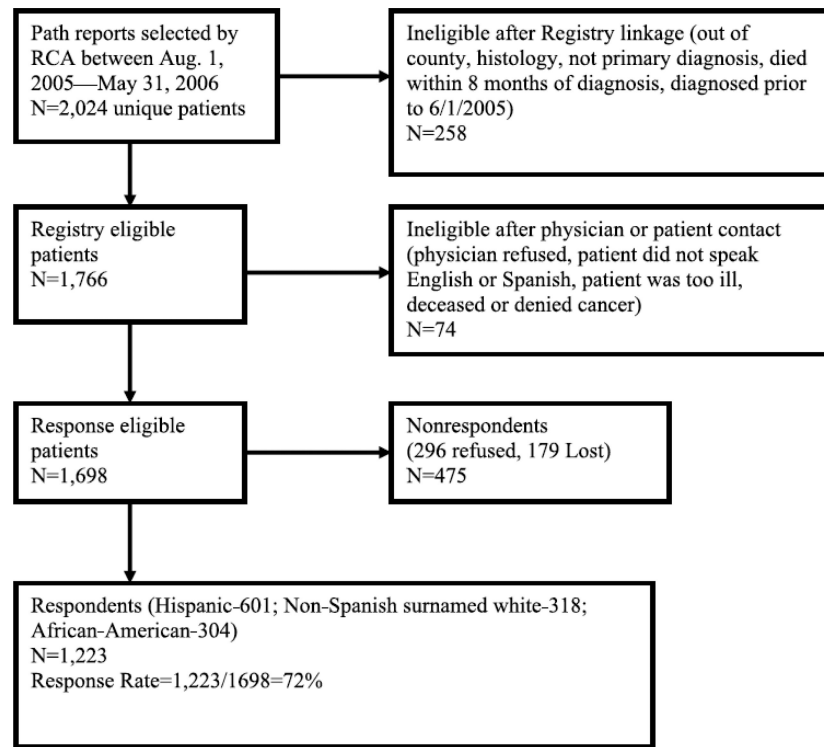
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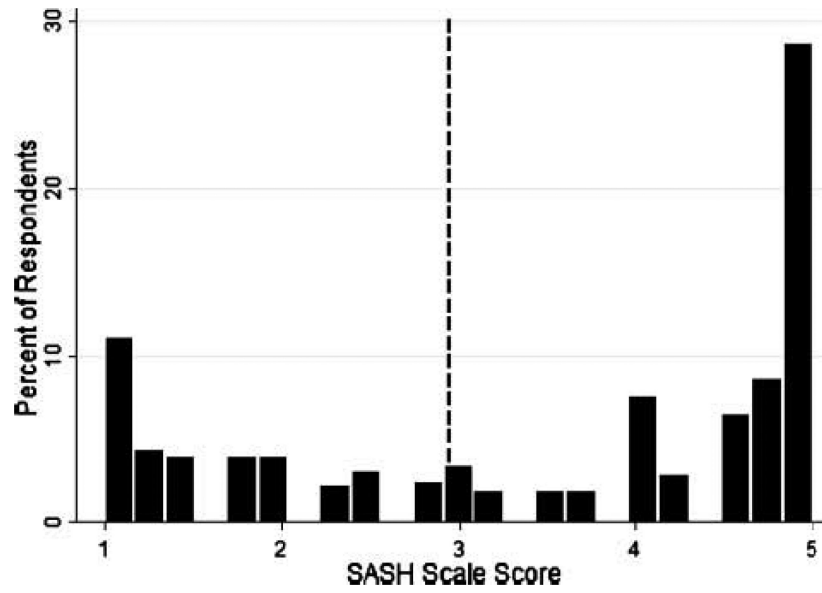
Figure 2.
Distribution of latina sample population by mean SASH scale score.

Table 1

Adjusted odds ratios for variables significantly associated with RCA sample selection (in addition to race/ethnicity) compared with all eligible cases ascertained by registry

Significant variables [*]	Adjusted odds ratios (95% confidence limits)	P
No surgery	0.65 (0.45-0.93)	0.02
Received radiation therapy	1.23 (1.05-1.44)	0.01
Received hormone therapy	1.23 (1.01-1.50)	0.03
Age (y)		
<45	1.00 (reference)	
45-54	0.79 (0.62-0.99)	0.04
55-64	0.70 (0.56-0.88)	0.002
65+	0.59 (0.47-0.73)	<0.0001
P trend = <0.0001		
Unknown tumor differentiation grade	0.63 (0.49-0.80)	0.0001

[*] Adjusted for race/ethnicity.

Table 2

Response to survey by race/ethnicity

Response	Hispanic[*]	NSSW	African-American	Total (%)
Completed questionnaire (total)	601 (71.4)	318 (77.6)	304 (68.2)	1,223 (72.0)
English	300	316	304	920
Spanish	301	2	0	303
Refused	149 (17.7)	57 (13.9)	90 (20.2)	296 (17.4)
Lost to follow-up/out of country	92 (10.9)	35 (8.5)	52 (11.7)	179 (10.6)
Total	842 (100.0)	410 (100.0)	446 (100.0)	1,698 (100.0)

[*] Based on RCA sample definition including both Spanish surname and/or hospital Hispanic identity.

Table 3

Selected demographic and clinical characteristics of respondents and nonrespondents

Selected characteristics	Respondents		Nonrespondents	
	N	*%*	*N*	*%*
Total	1,223	100.0	475	100.0
Age at diagnosis (y)				
<45	235	19.2	97	20.4
45-54	305	24.9	138	29.0
55-64	344	28.1	125	26.3
65+	339	27.7	115	24.2
Race/ethnicity (registry definition)				
Hispanic	558	45.6	207	43.6
African-American	302	24.7	141	29.7
NSSW	343	28.1	116	24.4
Other	20	1.2	11	2.3
Spanish surname				
Yes	572	46.8	218	45.9
No	651	53.2	257	54.1
Marital status [*]				
Single, never married	231	18.9	119	25.2
Married	657	53.7	224	47.2
Divorced, separated, widowed	298	24.4	107	22.5
Unknown	37	3.0	25	5.3
Socioeconomic status of census tract [†]				
High (1)	199	16.3	61	12.9
(2)	245	201	84	17.8
(3)	285	23.4	98	20.7
(4)	275	22.5	124	26.2
Low (5)	216	17.7	106	22.4
Stage of disease [*]				
In situ	238	19.5	93	19.6
I	445	364	132	27.8
II	350	28.7	142	30.0
III	142	11.6	73	15.4
Unknown	46	3.8	34	7.2
Type of surgery				
None	34	2.8	46	9.7
Lumpectomy	787	64.4	266	56.0
Mastectomy	402	32.9	163	34.3
Chemotherapy				
Yes	401	32.8	164	34.5

Selected characteristics	Respondents		Nonrespondents	
	N	*%*	*N*	*%*
No	822	67.2	401	65.5
Hormone therapy				
Yes	223	18.2	69	14.5
No	999	81.8	406	85.5
Radiation therapy[†]				
Yes	503	41.1	166	35.0
No	720	58.9	309	65.0
Tumor grade				
Grade 1	179	14.6	74	15.6
Grade 2	447	36.6	147	31.0
Grade 3-4	484	39.6	214	45.0
Unknown	113	9.2	40	8.4

[*] χ^2 $P < 0.005$.

[†] χ^2 $P < 0.05$.

Table 4

Sensitivity and specificity of different registry definitions of Hispanic identity using self-reported Hispanic/
Latina identification from the questionnaire as the gold standard

	Sensitivity	Sensitivity	Predictive value positive	Predictive value negative
RCA Spanish surname and/or Hispanic identity from hospital database	446	900	89.2	95.0
RCA Spanish surname (only)	99.5	92.3	91.3	90.6
SEER Spanish surname	90.2	90.4	89.0	91.4
SEER NHLA[*]	97.7	907	90.1	97.8

[*] NAACCR Hispanic Identification Algorithm.

Table 5

Distribution of selected acculturation-related measures by SASH summary score categories (*N* = 563)

	SASH score categories[*]				
	<2.0 (134)	2.0-2.9 (68)	3.0-3.9 (58)	4.0-4.9 (146)	5 (162)
Education[‡]					
Grade school or less	4.3	6.0	11.5	37.5	62.7
Some high school	17.1	15.0	23.1	22.9	18.7
High school graduate	20.0	22.4	19.2	25.0	12.7
Some college	45.7	29.9	30.8	11.1	4.0
College graduate	12.9	26.7	15.4	3.5	2.0
Country of origin					
United States	54.3	33.8	5.7	2.0	1.3
Mexico	32.9	51.5	66.0	68.5	68.4
Central America	5.7	1.5	7.6	21.3	20.1
Other Latin American	6.1	11.7	16.9	6.9	8.9
Other	1.0	1.5	3.8	1.3	1.3
Years in the United States[‡]					
<10	0.7	1.5	3.8	8.2	18.4
10-20	2.1	0.0	11.3	17.8	27.2
20	97.2	98.5	84.9	74.0	19.4
Parents born in the United States[‡]					
Neither	42.2	60.3	90.6	97.9	98.1
One	19.3	14.7	7.6	2.1	2.0
Both	42.2	25.0	1.9	0.0	0.0
Literacy[†],[‡]					
Difficulty with written information	2.4	5.8	5.8	6.0	11.6
Needed help with written information	14.8	20.6	19.0	44.1	57.2
Problems filling out forms	3.3	2.9	1.9	12.3	32.2

[*] Scale ranged from 1 (always speaking English) to 5 (always speaking Spanish).

[†] Percentage often/always.

[‡] *P*<.001 for differences across SASH categories.